



Long Term Care Coordinating Council
State Plan for Alzheimer's and Related Disorders Working Group

LTC Sub-Group

9:00 – 10:00 pm
Wednesday, December 19th, 2012
Elmhurst Extended Care
50 Maude Street
Providence, RI 02908

Present: Kathleen Kelly, Jim Nyberg, Drew Powers, Kathy Heren, Lindsay McAllister, Barbara Waterman, Laurie Johnson

1. Family Communication & Education in the Long-Term Care Setting
 - a. The group discussed the idea of approaching family support much in the way that Alcoholics Anonymous is structured. There would be a support meeting every week at the same time and place and people would show up on a week-to-week basis. This would be a meeting staffed with knowledgeable staff who could guide families to the resources they need. There would also be peer mentors, much like sponsors operate in the AA model.
 - b. There could be an email listserv caregivers could use to pose questions.
 - c. There should also be a better effort to meet the caregiver where they're at and at the level they need at any certain time. For example, at the time of intake, the caregiver would indicate the best way to communicate with them – be it email, blogging, phone, in person, etc.
 - d. The group also discussed using recertification and relicensure as triggers to incorporate dementia training into nurse and direct care staff education.
 - e. As a follow on to the earlier point, families want *one* communication tool. One portal that all caregivers can access to learn about the individual with dementia to integrate those specifics and those preferences into the care plan.
 - i. Marcia Werber Feldman mentioned that Charter Care uses a living document tool that she can share with the group as an example of this.

- f. Its also critical to include the person themselves in the creation of the care plan. This seems intuitive, but often the presumption is that the individual is unable to participate. They likely are, in fact, to some extent and this should be imprinted upon staff (and caregivers).
 - g. The group noted that not many nursing homes are tech-savvy or not able to implement an electronic medical records system in their facilities. Often, the primary mode of communication is in person or over the phone. This needs to be recognized in the recommendations that are included in the State Plan.
 - h. Deb Castellano also mentioned a 12 week Family-to-Family Class run through the Rhode Island NAMI office that might serve as a model for the type of peer-to-peer support the group was discussing. A link to more information on this course is below.
<http://www.namirhodeisland.org/education/education.htm>
2. The meeting was adjourned.